Consumer And Family Driven Mental Health Care

A White Paper by the North Dakota Mental Health Planning Council

April 21, 2006

Preface

A mental health planning and advisory council exists in every State and U.S. Territory as a result of federal law first enacted in 1986. The law requires States and Territories to perform mental health planning in order to receive federal Mental Health Block Grant funds. Stakeholders, including mental health consumers, their family members, and parents of children with serious emotional or behavioral disturbances, must be involved in these planning efforts through membership on the council.

States are required to submit yearly applications to receive federal block grant funds. The Mental Health Block Grant program is administered by the Center for Mental Health Services (CMHS), which is an agency of the Substance Abuse and Mental Health Services Administration (SAMHSA). The objective of block grant planning, in general, is to support the State creation and expansion of comprehensive, community-based systems of care for adults with serious mental illness and children with serious emotional disturbance. The goal of the Mental Health Block Grant program is to help individuals with serious mental illnesses lead independent and productive lives. The block grant program has served as an impetus in promoting and encouraging States to reduce the number of people receiving care in State psychiatric hospitals and to develop community-based systems of care.

In North Dakota, this group is called the Mental Health Planning Council (The Council). The Council consists of 27 members who are appointed by the Governor along with two ex officio members. Membership includes: representatives of the principle State agencies with respect to mental health, education, vocational rehabilitation, criminal justice, housing, and social services; public and private entities concerned with the need, planning, operation, funding, and use of mental health services and related support services; adults with serious mental illnesses who are receiving (or have received) mental health services (consumers); and the families of such adults or families of children with emotional disturbances.

A diverse membership brings vast strengths and varying perspectives to The Council. There is a shared knowledge of individual and general consumer situations, Medicaid, service delivery systems, reimbursement issues, housing and community development, legal issues, and community resources. Points of

view are presented from consumers of mental health services, family members, advocates, referral sources, schools, institutional and community-based service providers, the general disability community, and the criminal justice system. A majority of the membership has direct experience with issues concerning recovery, peer mentoring, service delivery, children's issues, and/or advocacy for mental health.

Introduction

The Council's current strategic plan is based on a federal report published in July 2003. Titled *Achieving the Promise: Transforming Mental Health Care in America*, the publication was written by the President's New Freedom Commission on Mental Health. The Commission was charged with studying the mental health service delivery system and to make recommendations that would enable adults with serious mental illnesses and children with serious emotional disturbance to live, work, learn, and participate fully in their communities.

The Commission's study resulted in six goals: 1) Americans understand that mental health is essential to overall health; 2) mental health care is consumer and family driven; 3) disparities in mental health services are eliminated; 4) early mental health screening, assessment, and referral to services are common practice; 5) excellent mental health care is delivered and research is accelerated; 6) technology is used to access mental health care and information.

Goal two of the Commission's report, also a goal of The Council's strategic plan, is that mental health care is consumer and family driven. The Council decided to write a white paper on this topic in order to provide its perspective on the existing service delivery system, related problems and concerns, as well as to offer solutions for policymakers and other stakeholders.

Perspectives on North Dakota's System for Mental Health Care

The "mental health care system" is a collective term referring to an array of programs for adults with mental illnesses and children with emotional disturbance. These programs are embedded in the Department of Human Services, schools, the juvenile and criminal justice systems, agencies that serve the homeless, disability services, and many others. They are in the public and the private sectors. Programs may provide treatment, services, and other supports directly or they may purchase these on behalf of the individual and/or family.

The mental health delivery system in North Dakota has a number of strengths. The state is relatively small in population and its provider population is small as well. North Dakota's mental health professionals know one another; they are collegial and supportive. People care about each other and want to help. Still, North Dakota is large geographically and needed services are not readily

available in some areas. There are children who are sent out of state, or hundreds of miles away within the state, to receive services.

The Department of Human Services provides mental health services directly through the eight regional human service centers and the North Dakota State Hospital. The regional human service centers serve consumers in the community through an array of services including: crisis stabilization and resolution; inpatient services; psychiatric/medical management; partial care/day treatment; social services; residential services and supports; vocational and educational services and supported employment; and social and leisure activities. The North Dakota State Hospital provides care to individuals with mental illness and/or substance abuse issues consisting of physical, medical, psychological, rehabilitative, social, recreational, and spiritual services.

The human service centers are licensed by the Department of Human Services. Administrative code mandates that the licensing team include a consumer or family member. Current licensing teams include both a consumer of mental health services and a family member of a consumer. The Council sees this as positive.

State rules prescribe standards for care plans for adults with serious mental illnesses who are served by a human service center (N.D.A.C. 75-05-04-03). The rules require that each individual have a plan, the overall development and implementation of which “are the responsibility of the professional staff member assigned the client”. A plan “must contain the client’s name, problems, service strategies to resolve problems, goals, names of staff members responsible for service strategies, and the signature of the case manager”. “The professional staff member assigned the client shall review the individual plan with the client and shall document the review in the client’s record”. For “clinical services, the case manager and the case manager’s supervisor shall review individual plans at least every six months, except for chronic cases, which must be reviewed at least every twelve months”. (N.D.A.C. 75-05-04-05)

Anecdotal conversations with consumers of mental health services reveal that many adults with a serious mental illness: 1) are NOT involved in the development of their plan of care; 2) have NOT seen their plan; 3) are NOT aware that they have a plan. In contrast, many adults with a serious mental illness have more than one plan, one through a residential provider and one developed by a case manager, which were not developed in concert with each other or with the participation (or even knowledge of) the consumer.

With changes to State law in the 2005 Legislative Session, it is now feasible for consumers to develop advanced directives for mental health care. Previously advanced directives were intended more generally for medical or physical care. Advanced directives allow individuals to make their own choices about treatment or care in advance of the need, when they are still capable of doing so.

As documented in North Dakota's Block Grant application, the wraparound process, which uses a strength-based approach to service delivery, is a method used that has "shown to improve the functioning of children who have complex needs. The process is used to help communities develop individualized plans of care. Working with the family, formal and natural supports (the child and family team) are wrapped around the family to provide them with the services/supports required to meet their needs. The wraparound process includes a set of core elements: 1) individualized plans of care, 2) culturally competent and tailored to the unique needs of families, 3) parental involvement, 4) strength-based, 5) least restrictive setting."

The Council believes that families involved in the *Partnerships Program for Children's Mental Health* have opportunities to collaborate on service plan development in conjunction with case management and service providers – it is a family driven process. It is not clear however, that families with children who receive case management but who are *not* in Partnerships have an opportunity for involvement in plan development. Many of these children have more than one plan, one through the school (an Individualized Education Plan or IEP) and one developed by or with a case manager, which were not developed in concert with each other.

As stated in the Block Grant application, the Division of Mental Health and Substance Abuse Services meets quarterly with each Human Service Center's program staff to plan and implement community-based mental health services statewide. It is further noted that the Human Service Centers regularly meet with regional stakeholders in addition to region-specific planning meetings that are held in every region throughout the year.[1] Discussion amongst consumers and family members indicate that there needs to be more focus on increasing the involvement of more consumers and family members in such activities.

Each of the eight human service centers provides for the operation of a psychosocial rehabilitation center that serves individuals with mental illnesses. The centers provide a minimum of forty hours of programming, including evening and weekend activities, seven days a week. Consumers who participate in center activities report that the programs are supportive, inclusive, and recovery-oriented. There are no such centers in the more rural communities.

The Council believes that the mental health consumer network in North Dakota needs strengthening. Over the years, the effectiveness and productivity of the consumer movement has fluctuated for a variety of reasons. A consistent, adequate funding source is needed to sustain its leadership and viability.

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[1] ND FFY 2006 CMHS MH Block Grant Application

A Consumer and Family Driven Mental Health Care System

*Consumers of mental health services must stand at the **center** of the system of care. Consumers' needs must drive the care and services that are provided.*

Achieving the Promise: Transforming Mental Health Care in America

The Council believes that a consumer and family driven mental health care system, with their involvement in planning, decision-making, implementation and review at all levels, will result in greater positive outcomes for individuals with mental illnesses and children with emotional disturbance. There will be a stronger "buy-in" by those who use the services as well as a higher rate of satisfaction with the services. More partnerships and collaboration will ensue, facilitating more meaningful communication and a higher level of trust between consumers and providers. The result is a better chance, for adult and child consumers, of recovery and resiliency.

In a consumer and family driven system, individuals' and families' needs drive the policies and service delivery system. Choice leads to greater participation and higher consumer satisfaction with services.

In *Achieving the Promise: Transforming Mental Health Care in America*, the President's New Freedom Commission on Mental Health states that providers should develop customized plans in full partnership with consumers and families of children. "The plans should form the basis for care that is both consumer-centered and coordinated across different programs and agencies."

Nothing about us without us…

Family member of The Council

The plan of care should not only describe the services and supports needed to achieve recovery, but the funding for the plan should follow the individual as identified in the plan. This takes a flexible funding mechanism. An example may be a young adult receiving inpatient acute care who, then for a short time, lives in a basic care facility. The consumer and his team develop a goal for independent living with community services and supports.

Recommendations

The following areas have been identified as current priorities under The Council's goal for mental health care to be consumer and family driven, along with a series of recommendations:

1. <u>Human service center licensure</u>
   a. Involvement of consumers <u>and</u> families on human service center licensure review teams should be mandated through State rules.

2. Individualized plans of care for adults with a serious mental illness
   a. State rules should recognize the consumer's right to participate in the development of the individual's plan of care, directly and through his/her legal decision-maker.
   b. After consulting consumers and their families, the Department should establish a protocol for development and implementation of single plans of care for adults receiving services from more than one provider.
   c. After consulting consumers and their families, the Department should develop standards for individual plan development, content, implementation and review that include consumer involvement at all levels.
   d. The Department should educate consumers and their families, including those on the Mental Health Planning Council, on the process for plan development, service options and the mental health delivery system generally.
   e. The Department should educate consumers on advanced directives and support them in the development of such plans.

3. Individualized plans of care for children with a serious emotional disturbance
   a. State rules should provide for the right of all families to participate in the development of the child's plan of care.
   b. With family input, the Department should establish a protocol for development and implementation of single plans of care for children receiving services from more than one provider.
   c. With family input, the Department should establish standards for plan development, content, implementation and review.

4. Involvement of consumers and families in orienting the mental health system toward recovery
   a. The Division and the Human Service Centers should broaden their approach, through psychosocial rehabilitation centers, service providers and the human service centers themselves, to informing consumers and families about stakeholder meetings and encourage their participation.
   b. The Council should hold periodic forums throughout the State with consumers and families to receive input on the mental health care service system.

5. Mental health services
   a. The Council should collaborate with the Department of Human Services regarding the viability of mental health services and, if the need warrants, potential expansion of support services into more rural communities in the State.

6. Mental health consumer network
   a. The Council's forums (recommendation 4.b.) should include discussion with consumers about their vision for a mental health consumer network (self advocacy movement) in North Dakota.

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